

DISABILITY AND REHABILITATION RESEARCH COALITION

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March 16, 2012

The Honorable Tom Harkin, Chair
Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
Committee on Appropriations
United States Senate
Dirksen Senate Office Building
Washington, DC 20510

The Honorable Richard C. Shelby, Ranking
Subcommittee on Labor, Health and
Human Services, Education and
Related Agencies
Committee on Appropriations
United States Senate
Dirksen Senate Office Building
Washington, DC 20510

RE: FY 2013 Appropriations for Disability and Rehabilitation Research Priorities

Dear Chair Harkin and Ranking Member Shelby:

Knowing of your commitment to enabling and empowering individuals with disabilities to live, function, and work in the mainstream of American society, the undersigned members of the Disability and Rehabilitation Research Coalition (“DRRC”)¹ urge you to consider including in the FY 2013 appropriations bill for Labor, Health and Human Services, Education and Related Agencies significant increased investment in disability and rehabilitation research (including capacity building and knowledge translation) across a number of federal agencies. DRRC is fully cognizant of the fiscal issues affecting our country.

We believe, however, that investments in disability and rehabilitation research today will not only enhance the quality of life of persons with disabilities, including veterans with disabilities, but will also result in significant mid-term and long-term savings to the federal government in regards to reduced reliance on Social Security programs, Medicaid and Medicare, and programs serving individuals with significant disabilities, including education, job training, housing, and veterans programs. Maximizing the functional capacity, employment, and independent living of people with disabilities translates into higher increased tax revenues and less dependency costs over time. In short, disability and rehabilitation research has a high return on investment.

Recent Institute of Medicine (IOM) studies on disability concluded that disability and rehabilitation research programs across federal agencies have been **chronically underfunded** for

¹ DRRC is a coalition of national non-profit organizations committed to improving the science of rehabilitation and disability. The DRRC seeks to maximize the return on the federal investment in disability and rehabilitation research with the goal of improving the ability of Americans with disabilities and chronic conditions to contribute to the health and economic well-being of our nation.

many years, especially considering the magnitude of the need for rehabilitation and disability services. Funding for rehabilitation and disability research is not in line with the current, and particularly, the future projected impact of disability on individuals, families, and American society. For example, *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, the 1997 IOM report on disability bluntly stated that the combined federal research effort was not adequate to address the needs of people with disabilities and that more funding would be required to expand research to meet these needs. According to *The Future of Disability in America* (the 2007 IOM report on disability), despite modest increases in funding, the situation essentially remains the same today.

As part of the FY 2013 Labor/HHS/Education/Related Agencies appropriations bill, we urge you to support significant increases for various agencies within the federal government conducting disability and rehabilitation research, capacity building, and/or knowledge translation of that research, including:

- **Funding** for the **Interagency Committee on Disability Research (ICDR)** to support the conduct of a disability and rehabilitation research summit and the development of a comprehensive government-wide strategic plan for disability and rehabilitation research, including capacity building and knowledge translation.
- **Report language** encouraging a greater recognition of, support for, and focus on disability and rehabilitation research at **NIH** through meaningful efforts by the Director and others.
- Increases in funding for the **National Institute on Disability and Rehabilitation Research (NIIDRR)** to support research and development, capacity building, and knowledge translation in the key life domains of employment, participation and community integration, and health and function as well as disability demographics and assistive technology.
- Increases in funding for disability and rehabilitation research initiatives at CDC and **report language** strongly supporting the disability-related programs under CDC and opposing budget consolidation efforts.
- **Report language** ensuring that research supported by **the Centers for Medicare & Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), and the Patient-Centered Outcome Research Institute (PCORI)** address the needs of individuals with disabilities and chronic conditions.
- Increases in funding for SAMHSA which would include demonstration projects to identify effective services to promote the recovery of individuals with serious behavioral health conditions, including those with co-occurring conditions. Also, the inclusion of **report language** urging SAMHSA to continue funding the development of new interventions, tools, services, and science-to-practice techniques to ensure access for individuals with behavioral health conditions/psychiatric disabilities and co-occurring or functional disorders, and those who serve or support them. Funding for these new developments should continue to be provided by SAMHSA, in conjunction with the National Institute on Disability and Rehabilitation.

SPECIFIC APPROPRIATION REQUESTS

Set out below is a more in depth justification for our specific recommendations.

1. Comprehensive Government-Wide Strategic Plan

The DRRC strongly urges the inclusion of **\$1.5 million** for the Interagency Committee on Disability Research (ICDR) to conduct a disability and rehabilitation research summit and support the development of a comprehensive government-wide strategic plan for disability and rehabilitation research, including knowledge translation. ICDR was established by Congress (Section 203 of the Rehabilitation Act) to promote the coordination and cooperation among federal departments and agencies conducting disability and rehabilitation research.

In addition, DRRC strongly recommends the inclusion of **report language** directing ICDR to conduct a disability and rehabilitation research summit and develop a comprehensive government-wide strategic plan for disability and rehabilitation research, including knowledge translation. The Summit should bring together policymakers, representatives from Federal agencies conducting disability and rehabilitation research, nongovernmental funders of rehabilitation research, and organizations representing individuals with disabilities, researchers, and disability and rehabilitation service providers. The strategic plan should include, but not be limited to: research priorities and recommendations; a set of guiding principles and policies and procedures for conducting and administering such research across Federal agencies; a summary of underemphasized and of duplicative areas of research; and the development of a searchable government-wide inventory of disability and rehabilitation research for trend and data analysis across Federal agencies. The strategic plan should be submitted to the President and the House and Senate committees of jurisdiction. The ICDF annual report should include annual accounting of progress made in implementing the strategic plan, including the achievement of measureable goals and objectives, timetables, budgets, and the assignment of responsible agencies and individuals.

2. Medical Rehabilitation at NIH

As you know, medical rehabilitation and disability research at NIH is currently conducted at the National Center for Medical Rehabilitation Research (NCMRR) (currently housed within the National Institute of Child Health and Human Development) and across NIH. DRRC is pleased that NIH has taken steps to establish a Blue Ribbon Panel to complete a comprehensive landscape surveillance of the different agency's research efforts to identify gaps in rehabilitation research. Consistent with two recent reports by the Institute of Medicine, DRRC continues to believe that NCMRR needs to be elevated to a freestanding Institute or Center within NIH. There is a need for a high profile entity within NIH that has medical rehabilitation and disability research as its primary mission and that appropriately occupies an organizational level that reflects this primary mission. There is a concomitant need for enhanced stature, emphasis, and leadership at NIH relating to medical rehabilitation and disability research in order to garner the attention of other institute and center directors and to coordinate and collaborate on rehabilitation

science that cuts across the multiple institutes and centers. DRRC recommends the inclusion of the following **report language** accompanying the bill:

“The Committee recognizes and supports efforts of the Blue Ribbon Panel to complete a comprehensive landscape surveillance of the different agency’s research efforts to identify gaps in rehabilitation research i.e., research which recognizes the science of human function, human activity and human enablement. The Committee understands that rehabilitation research is fundamentally different from the study of particular diseases and their prevention and cure. The Committee continues to believe that the findings of the Blue Ribbon Panel should result in meaningful administrative steps by the Director to enhance the stature, emphasis, and leadership at NIH relating to medical rehabilitation and disability research in order to garner the attention of other institutes and center directors and to coordinate and collaborate on rehabilitation sciences across the multiple institutes and centers.”

3. National Institute on Disability and Rehabilitation Research (NIDRR)

The DRRC urges **significant funding increases for NIDRR over the next five years (\$20 million per year)** to support NIDRR’s mission-oriented agenda. This DRRC recommendation constitutes a dramatic increase in funding at a time when federal budget conditions are at their most difficult. But this recommendation reflects the high return on investment that DRRC believes will come with increases funding for rehabilitation and disability research.

Since Congress established NIDRR in 1978, it has served as the flagship federal agency on disability and rehabilitation research. NIDRR’s mission has been to explore the interaction of individual characteristics and environmental factors and their effects on the participation of individuals with disabilities of all ages in the home, community, school and workplace. Thus, NIDRR’s mission includes exploring new and innovative strategies, interventions, and technologies to better achieve the promises of the Americans with Disabilities Act—equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities. NIDRR carries out its mission by generating new knowledge through research and development in the major life domains of employment, participation and community integration, and health and function; promoting its effective use (knowledge translation), and building the capacity of institutions and individuals to conduct high quality research and development.

Unfortunately, NIDRR’s ability to fulfill its mission has been severely hampered by the lack of adequate funding—NIDRR’s funding has been virtually flat for many years now.

The doubling of funding for NIDRR over the next five years would support:

- Research and Development in General, including:
 - Expanding the field initiated research program which offers significant opportunity to expand knowledge and create a basis for more advanced research (a significant barrier to the growth of evidence-based rehabilitation

practice is the limits on funding for testing hypotheses at an early stage of research development);

- Improving the advanced research portfolio (which supports multi-site research, especially with its model systems program for TBI, SCI and burn) and expanding the advanced research portfolio to focus on other areas such as stroke, arthritis, and psychiatric disabilities;
 - Evaluating the capacity of the American health and post-acute care systems to meet the health, behavioral, functional, and rehabilitation need of individuals with disabilities; and
 - Improving the infrastructure for outcome-based research by funding the development of more specific measures and outcomes of particular relevance to people with disabilities. There is a need for increased support for development and testing of adequate instruments for measuring the effectiveness of specific medical rehabilitation interventions and their duration or setting, as well as measuring the effectiveness of specific psychiatric interventions and functional recovery. A major expansion of research is necessary to develop measurement approaches for disability that will assist in research regarding the outcomes of specific rehabilitation interventions and measuring the independence of the person with a disability in community living and the job environment.
- Research and Development in Particular, including:
 - Expanding medical and rehabilitation strategies (e.g., combination of technological, clinical, and community interventions) for people aging with and aging into disability (current research portfolio is very limited and thus does not adequately address the changing demographics described above);
 - Expanding and improving medical and rehabilitation strategies for infants and young persons with disabilities (congenital and well as acquired);
 - Better understanding about life-span/developmental issues as they differentially impact individuals with disabilities (e.g., are medications used to treat diverse medical and psychiatric conditions in individuals without chronic disabilities effective in treating individuals with disabilities?);
 - Better understanding how key life transitions (e.g., school to work and work to retirement) are impacted by disability;
 - Supporting rigorous research on employment, vocational rehabilitation, and other interventions to address the dismal employment rate of persons with disabilities;
 - Supporting research on the types of supports needed by individuals with disabilities to live in the community (rather than in institutions) and the use of social networks to decrease isolation and alienation;
 - Supporting research regarding the application of new technologies and communication modalities (e.g., Facebook) to the lives of persons with disabilities.
 - Capacity building (addressing the insufficient numbers of adequately prepared rehabilitation researchers), including:

- Supporting the development of models of interdisciplinary collaboration, which is critical given the diversity of people, interventions, and environments that are the subject of disability and rehabilitation research;
 - Supporting the development of effective models of clinical research short of clinical trials as well as the infrastructure for the complex and demanding clinical research area;
 - Supporting predoctoral training in rehabilitation research; and
 - Expanding funding for advanced research training for post-doctoral training in rehabilitation research.
- Knowledge translation, including expanding support for taking the findings from rigorous and relevant research and effectively translating them into usable practices and training provided to practitioners as well as funneling promising practices from the field back into the research agenda. Additional support is needed across NIDRR's entire portfolio to facilitate the use of NIDRR research. There is also a need to support additional efforts to provide knowledge and consultation to entities that have a duty to implement the ADA.

DRRC also recommends the inclusion of the following report language:

“The Committee strongly supports the mission of NIDRR as the flagship Federal agency on disability and rehabilitation research, which includes research in the interrelated domains of health and function, employment, and participation and community living. NIDRR's resources should focus on each of these statutory research priorities to ensure the advancement of economic and social self-sufficiency and full community inclusion and participation of individuals with disabilities. The Committee urges the Secretary to embrace NIDRR's mission and enhance its stature and visibility within the Department. The Committee urges the NIDRR director to focus additional attention on knowledge translation and ensuring that the practical implications of research outcomes are summarized and research activities and findings will be made publically available in a timely manner in order to inform the public about the research activities it supports.”

4. Centers for Disease Control and Prevention (CDC).

DRRC believes a strong disability and health program at CDC is critical to promoting the health and well-being of persons with disabilities. DRRC supports the appointment by Dr. Frieden of a chief disability and health officer and the establishment of a disability and health group at CDC as a positive step forward. However, DRRC is gravely concerned with the reductions in funding for disability and rehabilitation-related programs and proposals to consolidate budget line items. DRRC also acknowledges that the President's FY 2013 budget proposal would “refinance” 86% of NCBDDD using the Prevention and Public Health Fund. DRRC requests a stable and permanent funding base for NCBDDD.

Specifically, DRRC recommends that Congress provides at least **\$137.3 million** in FY 2013 (level funding) to sustain the vital programs and activities funded by the **National Center on Birth Defects and Developmental Disabilities**, of which \$119.3 million should be allocated to birth defects and disability programs.

DRRC also recommends at least **\$56.5 million** be appropriated in FY 2013 (level funding) and directed to CDC's **Division of Disability and Health Development** to maintain support for, among other things, research on risk factors and measures of health, functioning and disability. Continued funding for research will address knowledge gaps in promoting health of people with disabilities.

In addition, we urge additional funding be provided to the **Center for Injury Control and Prevention** to expand and improve support for tertiary prevention (i.e., rehabilitation) of conditions such as traumatic brain injury and spinal cord injury. Specifically, DRRC recommends an increase in funding of the 11 Injury Control Research Centers from the current \$905,000 per year to \$1,250,000 per year (the program has been cut back since 2007). Priorities for research should include support for pediatric injury surveillance efforts, including for example, recognition of traumatic brain injury as a disease; improved identification, assessment, and management of conditions; development and application of methods for calculating population-based estimates of the incidence, costs, and long-term consequences of conditions; identification of methods and strategies to ensure that individuals with specified conditions receive needed services; and the development and evaluations of the effectiveness of interventions.

DRRC recommends that the Committee include the following **report language**:

“The Committee is encouraged by the Director’s decision to appoint a CDC chief disability and health officer and the establishment of a disability and health work group at CDC, which recently prepared its one-year progress report. The Committee encourages the work group and the key program operating components in CDC to continue to address ongoing strategic efforts to support and strengthen public health research activities focused on people with disabilities: recognizing disability as a key determinant in national surveys and other surveillance systems and public health programs; addressing health disparities among people with disabilities; enhancing health promotion and prevention and access to health care for people with disabilities; fostering knowledge translation and communication efforts to bring persons with disabilities reliable information on a variety of public health topics; developing new disability research initiatives through partnerships across CDC Centers and other federal agencies; and developing public and private partnerships to support and advance disability issues.”

The Committee is greatly concerned, however, and has significant reservations about the budget consolidation that CDC has proposed for disability initiatives, particularly the proposal for consolidating birth defects and developmental disabilities activities into three budget lines. The Committee believes that, as proposed, such a consolidation would jeopardize the progress that has been made on behalf of people with disabilities, as well as the partnerships that have developed. The Committee rejects the consolidation proposed in the fiscal year 2013 budget for disability initiatives in NCBDDD and directs that any new consolidation put forward by CDC be accompanied by an assessment of the needs of people with disabilities that includes the categories of disabilities currently

served, validates the value of such a consolidation, considers the impact of stakeholders, and establishes the basis of any proposed efficiencies and commonalities.”

5. Centers for Medicare & Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), and the Patient-Centered Outcome Research Institute (PCORI).

Throughout the disability and rehabilitation fields, efficacy research must be enhanced and made a priority. Insufficient research is having a deleterious impact on the provision of quality, technologically-advanced rehabilitation services, supports, treatments, and devices. As all payers look to research-based evidence to assess the efficacy and medical necessity of various healthcare interventions, it is critical that the field of rehabilitation, which has a paucity of research evidence, not get left behind. There is a need for more efficacy research to prevent the lack of sufficient evidence on effectiveness from being misread as evidence of lack of effectiveness.

There is also a need for increased support for development and testing of adequate instruments for measuring the effectiveness of specific medical and psychiatric rehabilitation interventions and their duration or setting. In addition, there is a need for increased support for the development and testing of adequate instruments for the effectiveness of specific psychiatric interventions on the capacity of individuals for functional recovery. A major expansion of research is necessary to develop measurement approaches for disability that will assist in research regarding the outcomes of specific rehabilitation interventions and measuring the independence of the person with a disability in community living and the job environment.

At the same time, it is critical to recognize the criteria developed by the U.S. Preventive Services Task Force for evidence stratification and assessment in ranking treatment effectiveness. DRRC encourages the use of the criteria below, including Level II and Level III studies to inform treatment guidelines:

Level I: Evidence obtained from at least one properly designed randomized controlled trial (RCT).

Level II-1: Evidence obtained from well-designed controlled trials without randomization.

Level II-2: Evidence obtained from well-designed cohort or case-control analytic studies, preferably from more than one center or research group.

Level II-3: Evidence obtained from multiple time series with or without the intervention. Dramatic results in uncontrolled trials might also be regarded as this type of evidence.

Level III: Opinions of respected authorities, based on clinical experience, descriptive studies, or reports of expert committees.

DRRC also understands the intent of comparative effectiveness research (CER) is to inform practitioners and patients of the relative risks and benefits of options when making treatment decisions. CER is not intended as a tool for denying patients access to needed care based on best practices, and in fact, the use of evidence-based medicine for such purposes is specifically denounced in state laws as well as the Affordable Care Act. Accordingly, it is important to

recognize that the absence of an RCT does not equate to the absence of evidence. Similarly, the inability to draw conclusions about the comparative effectiveness of a treatment does not mean the treatment is ineffective. DRRC urges AHRQ and PCORI to take the utmost care in articulating research conclusions.

DRRC recommends the inclusion of **report language** urging CMS in conjunction with AHRQ to make a substantial commitment to better support efficacy studies designed to document the input and output of rehabilitation interventions concerning particular rehabilitation services, supports, treatments, and technologies. For example, research needs to be funded (including large scale randomized clinical trials, \$2M-\$5M per trial) to develop unambiguous functional and medical appropriateness standards that will make it possible for patients to be admitted to the proper rehabilitation care setting without the need for federal enforcement authorities to retroactively review and deny coverage and payment to providers of care. DRRC also recommends report language urging AHRQ and PCORI include in its research portfolio a focus on disabilities and chronic conditions; include disability as a disparity in research that measures disparities related to health outcomes; and encourage the use of all three levels of evidence stratification and assessment recognized by the U.S. Preventive Services Task Force and recognize that the absence of a randomized controlled trial does not equate to the absence of evidence. Similarly, it is critical that AHRQ and PCORI recognize that the inability to draw conclusions about the comparative effectiveness of a treatment does not mean the treatment is ineffective.

6. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

DRRC recognizes the important role that SAMHSA has played relative to many Americans with disabilities. Behavioral health is a component of service systems that improve health status and contain health care and other costs to society. Yet, people with mental and substance use disorders, because of their illness, have largely been excluded from the current health care system and rely on public "safety net" programs. The Substance Abuse and Mental Health Services Administration's (SAMHSA) mission is to reduce the impact of substance abuse and mental illness on America's communities through leadership in the development of treatment, prevention and recovery support services for individuals with psychiatric and substance abuse related disabilities.

To accomplish this mission, SAMHSA has developed an Eight Point Strategic Initiative outlined in *Leading Change: A Plan for SAMHSA's Roles and Actions 2011-201*. The Recovery Supports and Public Awareness initiatives within this plan are based on the premise that people of all ages, with or at risk for mental or substance use disorders should have the opportunity for a fulfilling life that includes a job/education, a home, and meaningful personal relationships with friends and family. SAMHSA's role within that vision is to provide national leadership to expand the availability of effective treatment, prevention and recovery services for persons with mental illnesses and/or alcohol and drug problems, as well as monitor ADA compliance within settings that fall under their purview.

Emerging research indicates that persons with severe mental illness experience additional conditions that impact their ability to function within the community. These co-occurring or

other functional disorders can include substance use disorder, hidden traumatic brain injury, chronic medical conditions, or other conditions. Rates of substance use disorders have been shown to be higher for persons with disabilities, yet access to treatment is limited or in some cases almost non-existent. Transitioning youth with disabilities often have no access to substance abuse prevention education, although drug use initiation has been shown to impact future school and vocational success.

DRRC recommends expanding funding for SAMHSA in order to better serve persons with serious behavioral health conditions, including those with co-occurring or other functional disorders. This should include expanded funding to address poly co-morbidity in CMHS, and co-occurring and other function disorders in CSAT and CSAP. Increased funding for SAMHSA would include **\$4 million** for CMHS for funding or co-funding of recovery and public awareness demonstration programs targeted for those serving individuals with serious behavioral health conditions, including those with co occurring conditions, **\$5 million** for joint funding with NIDRR of Rehabilitation Research and Training Centers in Adult and Children's Serious Mental Illnesses, **\$3 million** for CSAT to fund programs focused on those with serious behavioral health conditions, including those with co occurring conditions, and **\$3 million** for substance abuse prevention programs focused on youth with serious behavioral health conditions.

We recommend the inclusion of **report language** urging SAMHSA to continue funding the development of new interventions, tools, services, and science-to-practice techniques to ensure access for individuals with behavioral health conditions/psychiatric disabilities and co-occurring or functional disorders, and those who serve or support them. Funding for these new developments should continue to be provided by SAMHSA, in conjunction with the National Institute on Disability and Rehabilitation.

If you have any questions, please contact Bobby Silverstein or Peter Thomas at 202.466.6550. Bobby's email is bobby.silverstein@ppsv.com and Peter's email is peter.thomas@ppsv.com.

Sincerely,



Robert Silverstein



Peter W. Thomas

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American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association of Spinal Cord Injury Nurses
American Association of Spinal Cord Injury Psychologists and Social Workers
American Association on Health and Disability
American Congress of Rehabilitation Medicine
American Hospital Association
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Therapeutic Recreation Association
Amputee Coalition of America
ARA Institute
Arthritis Foundation
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Brain Injury Association of America
Christopher and Dana Reeve Foundation
Disability Rights Education and Defense Fund
Federation for American Hospitals
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Council on Independent Living
National Spinal Cord Injury Association
National Multiple Sclerosis Society
Paralyzed Veterans of America
RESNA
United Spinal Association